

Agenda

Amstel room, 1st floor

Leonardo Royal Hotel Amsterdam

Paul van Vlissingenstraat 24

1096 BK, Amsterdam, The Netherlands

<https://www.leonardoroyalhotelamsterdam.com/>



Friday, 10 November 2023

17:00 - 18:30 Optional carotid artery screening* (offsite, limited space, registration required)

19:00 - 19:30 Networking reception (Leo's restaurant, ground floor)

19:30 - 22:00 Dinner and Networking (buffet style, Leo's restaurant, ground floor)

Saturday, 11 November 2023

8:30 - 8:50 Hypopressives** (morning warm up) with Emma Print

9:00 - 9:20 Welcome to the FH Europe Foundation 1st Annual Network Meeting 2023

- Nicola Bedlington - FHEF, Sr Policy Advisor, Moderator
- John Reeve - FHEF, President
- Prof. Albert Wiegman - Dutch Host and Programme Co-Chair
- Magdalena Daccord – FHEF, Chief Executive Officer

9:20 - 10:45 The current international health landscape - Together, engaged for change

- *Familiar Hyperlipidaemias – everything that connects us*, Prof. Albert Wiegman, 20'
- *The importance of patient engagement in advocating for change. The Regulator's Perspective*, Maria Mavris (EMA), 20'
- *Lp(a) International Taskforce – the catalyst project*, Prof. Florian Kronenberg /Nicola Bedlington, online and in person, 20'
- *A Cardiovascular Health Plan for Europe - the political opportunity for change* James Kennedy (ESC/ EACH), online, 15'
- *Discussion*, ALL, 10'

10:45 - 11:00 Active break

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Saturday, 11 November 2023

11:00 - 12:30 Evidence – a critical element for successful implementation

- *Registries – from individual data sets to building the bigger picture* - Christophe Stevens and Kanika S. Dharmayat, EAS FH Studies Collaboration, in person and online, 25'
- *Health economics and cost-effectiveness of screening – a powerful advocacy argument for implementation* - Prof. Zanfina Ademi, 20'
- *Precision Health: the role of the social and behavioural sciences in advancing implementation* - Dr Marius Geanta, FHEF, 15'
- *Collaboration for impact, from research to person-centred care* - Prof. Mafalda Bourbon, 15'
- *Women's data – the missing piece in women's health protection, disease prevention and care* - Prof. Kirsten Holven, 15'

12:30 - 13:30 Lunch & Networking

13:30 - 15:00 **Workshop 1: The patient journey – a basis for advocacy and support**

- Plenary introduction - Magdalena Daccord/Nicola Bedlington
- Sub-groups in breakout rooms

15:00 - 15:30 **Active break/Dietary expert advice*** with Prof. Kirsten Holven and Emma Print**

15:30 - 16:45 **Workshop 2: The Ambassadors Programme – empowerment through education – review**

- Plenary introduction - Elsie Evans, Ambassador Programme Manager
- Sub-groups in breakout rooms

16:45 - 17:00 **Closing remarks** - Nicola Bedlington and Magdalena Daccord

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Saturday 11 November 2023

17:00 - 19:30 FREE TIME

17:15 – 18:45 **Optional carotid artery screening***

19:30 - 22:00 **Gala Dinner** with the introduction of the Artistic Ambassador and Award for Life Achievements (Amstel 3, 1st floor)

Sunday 12 November 2023

8:30 – 8:50 **Hypopressives**** with Emma Print

9:00 - 9:15 **Welcome to the 2nd Day – objectives**, John Reeve and Magdalena Daccord

9:15 - 10:15 **Debrief from the Workshops** –Jill Praver, Rare Disease Manager

10:15 - 10:45 **Finance report, funding and new opportunities** - John Reeve

FH Europe/FHEF Report to date - Magdalena Daccord

10:45 - 11:15 **Active break**

11:15 - 12:45 **Community Engagement**

- **Membership model, Ambassadors' Groups, Rules of Engagement** - Emma Print, Community Engagement Manager, 15'
- **FH Europe Foundation Work Programme 2024** - Magdalena Daccord, 20'
- **Ambassadors of the future** - the Youth Group - Elsie Evans, 10'
- **Collaboration and evolution to keep relevant – Czech Republic** - CAKO, Krystina Cillikova, 15'
- **Discussion: How can members be involved?** - facilitated by Emma Print, 30'

12:45 - 13:00 **Closing remarks and the next annual meeting**

13:00 - 14:00 **Lunch & Departure**

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***Optional carotid artery screening** – Screening exams find disease before symptoms begin. The goal of screening is to detect disease at its earliest and most treatable stage. In order to be widely accepted and recommended by medical practitioners, a screening program must meet a number of criteria, including reducing the number of deaths from the given disease. Read more:

<https://www.radiologyinfo.org/en/info/screening-carotid>

This fantastic opportunity is offered by Prof Albert Wiegman and his Team at the Amsterdam University Medical Centres. Max 6 persons on Friday and max 6 persons on Saturday. On a “First come, first served basis”.

The screening will take place at the Amsterdam University Medical Centres, 10min drive away from the hotel. Transport will be organized to and from the medical centre. Any taxi costs outside of the provided transfer will not be reimbursed.

To register send a **WhatsApp to Spela Bovha on +386 31 703 580.**

****Hypopressives** – is a whole-body training approach using breathing and postural techniques to create positive changes in the core, pelvic floor, and your posture. Read more: <http://lifeacrobat.com/what-we-do/hypopressives/> .

This fantastic way to start your day at the meeting is offered by Emma Print, our Community Engagement Manager. No special clothes required. Open to all, on both mornings before the plenary session in the plenary room from 8:30am.

***** Dietary expert advice** – nutrition, food, eating are key components of day-to-day management of the inherited lipid conditions. They are often challenging as local diets differ, adequate professional expert advice is missing and access to some foods may be challenging. Finally, not everyone is a born chef... Sometimes however simple tips and clarification can be a game changer.

Meet Prof Kirsten Hoven and Emma Print, who specialise in nutrition and healthy diet, to ask questions related to cholesterol, triglycerides, and so on. They will be happy to support you on the spot or maybe post event with more precise answers. This fantastic opportunity is open to all participants during the afternoon coffee break on Saturday afternoon.

For more information reach out to Emma on Emma@fheurope.org .